



# **NATIONAL BIOETHICS CONSULTATIVE COMMITTEE**

REPORT TO

THE AUSTRALIAN HEALTH MINISTERS' CONFERENCE

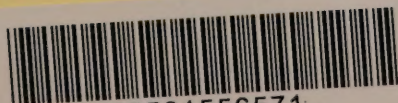
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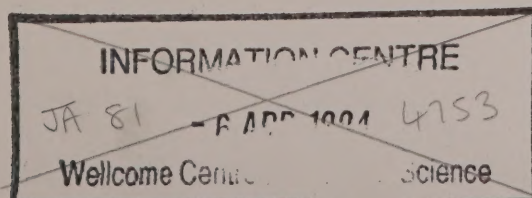
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## 1. CHAIRPERSON'S REPORT

I am pleased to submit to the Australian Health Ministers' Conference the first Report of the National Bioethics Consultative Committee for the period March 1988 to March 1989. This Report has been specifically prepared for the annual meeting of your Conference. A more detailed Annual Report of the Committee covering the full financial year will be available for public distribution after July 1989.

The Committee membership was announced by the Hon Neal Blewett, MP, Minister for Community Services and Health on 18 March 1988, however, the Committee was not given any references for its consideration until July 1988 upon referral from the Council of Social Welfare Ministers. Therefore, the first meeting of the Committee was delayed until August 1988.

Although the Committee first met five months after its formal establishment, this time was usefully deployed in the members of the Committee having some lead time to acquaint themselves with appropriate literature. The Executive Director and I visited a number of States and met with Ministers and their staff, departmental officers, attended various conferences and met with ethics organisations. These meetings and conferences performed a dual role of being instructive for us as well as providing us with an opportunity to inform others about the functions and roles of the Committee. In addition, the Executive Director and I visited the United States of America for three weeks. This trip, funded by the Department of Community Services and Health, was a source of valuable information for use by the Committee and other ethics organisations as detailed in our report, "Bioethics Organisations in the USA". [Appendix 1]



The Committee, over the remaining six months, has been most productive. It has completed three background papers on "Surrogacy", [Appendix 2] "Access to Information - An Analogy between Adoption and the use of Gamete Donation" and "Developments in the Health Field with Bioethical Implications". [Appendix 4]. One of these papers has already been distributed to persons and organisations on our mailing list, and the others will be similarly distributed. Furthermore, a final report on two of the references, namely "Record Keeping and Access to Information" and "Birth Certificates and Birth Records of Children Born of Gamete Donation" will be submitted to you in the near future following circulation for public comment.

Whilst we have had only three meetings of the Committee and it is therefore still early days, the Committee and the Working Parties appear to work efficiently. Our experience is that each report requires consideration at two or three meetings of a Working Party as well as two meetings of the Committee. This means reports take approximately six months for completion of a draft from the first committee consideration and thereafter further period of 2 to 3 months must be added to allow for public comment. As the issues referred to the Committee are considered universally to be complex matters with potentially profound long-term implications, I believe the time frame established by the Committee to be justifiable. This time frame compares more than favourably with the United States experience, in which reports by equivalent organisations take an average of twelve months for completion of the draft. However, we consider that this process could be improved, both as to time of consideration by the Committee and quality, if the number of meetings of the Committee were increased to, say, five or six in a year instead of four, which we will be holding this financial year. Further discussion of this occurs in Chapter 6 of this Report.



I am pleased with the productivity of the Committee over the period, particularly taking into account the delay in commencement, and also, the problems attendant on a change in the Secretariat from Canberra to Adelaide which included a complete change of staff. In spite of the best endeavours of the Department and the dedication of the staff to make the handover occur as smoothly as possible, it has been disruptive and has placed a greater load on the Secretariat and myself in informing and grooming people for their work, and a subsequent delay in the Committee's work.

The late forwarding of references has also meant under-spending of budget which will not be reflected in the next financial year. The focus of the Committee and Secretariat, in this initial period, was in establishing an infrastructure for their operation and planning their activities around the references proposed. With the structures and work plan now in place, the Committee is eager to continue its work and plan for future references. Chapter 7 identifies areas that the Committee believes require further attention.

The immediate future challenges for the Committee are to finalise, following public consultation, the report pertaining to "Record Keeping and Access to Information" and "Birth Certificates and Birth Records of Children Born of Gamete Donation", produce a report on "Surrogacy", which is well under way; and develop plans for the report on "Counselling". These reports plus an update of "Major New Developments in the Health Care Field" will be finalised during the ensuing year and will be formally presented to you at your next meeting, for consideration and referral to the Council of Social Welfare Ministers.

The Committee looks forward to the exciting challenges and opportunities it will face this year. I am confident that the Committee possesses the appropriate skills and has an effective Secretariat to undertake the work which has already been given, as well as any future references.

ROBYN LAYTON



## 2. GENERAL OVERVIEW

### 2.1 Background

In 1985, Senator Harradine brought forward the Human Experimentation Bill 1985 which proposed the prohibition of human embryo experimentation with associated criminal penalties, and allowed for injunctions to be sought restraining institutions or persons from engaging in experimentation. During the debate on the Bill, concern was expressed that the injunction procedure, together with the imposition of criminal penalties, would bring about the cessation of research relating to In Vitro Fertilisation [IVF] in Australia.

In response to the Bill, a Senate Select Committee was established in October 1985 to examine the need for research on embryos in the context of IVF programs, the necessity for guidelines for research, and the Bill's proposals for certain research to be prohibited.

The Senate Committee reported in October 1986. Although their recommendations were not unanimous, the majority of the Committee favoured on the setting up of a national regulatory body, to accredit and license, based on a national legislation.

In February 1984, the Family Law Council established a sub-committee to report on the issues raised by reproductive technology. The principal recommendation, contained in the Council's report "Creating Children", was that there should be a national approach to the range of issues arising out of reproductive technology and that a National Council on Reproductive Technology be formed. Such body should be multi-disciplinary with lay representation and should be established to advise Commonwealth and State Governments on matters of mutual concern.



Following recommendations by both the Family Law Council and Senate Committee reports, the Commonwealth Government consulted with the States and Territories through the Australian Health Ministers Conference [AMHC] and the Standing Committee of Attorney's General [SCAG] and the Council of Social Welfare Ministers. [CSWM].

All States supported the concept of establishing a consultative body with responsibilities for providing advice to Federal and State Governments on the full range of issues arising from reproductive technology with a national perspective to common issues.

Many States had already commissioned reports from commissions of inquiry into issues related to the practice of artificial conception. These bodies focused on various subjects and their recommendations led the States to different courses of action. It is clear from the findings of these State Enquiries that no consensus of expert and political opinion exists on these profound and complex issues in Australia at this time. It was envisaged that a national multi disciplinary body could provide a wider forum for ideas and issues to be publicly debated and analysed.

In March 1988, the National Bioethics Consultative Committee was formed after consultation as to membership and function with all States through AMHC, SCAG and CSWM.

### 3. ROLE AND STRUCTURE OF THE COMMITTEE

#### 3.1 Functions

The Committee's functions are governed primarily by its Terms of Reference. Specifically, these functions are :

- . to provide advice and undertake studies on matters as requested by the AHMC on the ethical, legal and social issues arising from :
  - reproductive technology including human embryo experimentation and the bearing of children;
  - biomedical and health related research;
  - the application of scientific and medical technology;
  - the provision and delivery of health services.
- . The Standing Committee of Attorney-General and the Council of Social Welfare Ministers may forward issues of concern to the Ministerial Council which may refer them to the Committee if this is considered appropriate.

#### 3.2 Committee Procedures

The documentation which contains these Terms of Reference also includes some modus operandi for the Committee. These modus operandi were further expanded by the Committee at its first meeting in August 1988 in which amended recommendations made by the Chairperson and Secretariat following the trip to the USA were adopted by the Committee. The expanded committee procedures adopted by the Committee covered topics such as :



- . public statements by Committee members;
- . public media role;
- . confidentiality of Committee proceedings;
- . staff requirements to service the Committee;
- . liaison between Chairperson and staff;
- . meeting procedures for either closed or open meeting;
- . meeting procedures and roles of Working Parties;
- . report requirements and procedures.

### 3.3 Goals

The Goals of the Committee were prepared and later adopted at the third meeting in February 1989, as follows :

- . to provide high quality advice and information on bioethical issues to the Australian Health Ministers;
- . to encourage communication and information exchange between the Committee and major bioethics organisations;
- . to encourage communication and information exchange between the Committee and Federal, State and Territory organisations on bioethics issues;
- . to promote debate in the community on bioethical issues contained in references to the Committee;
- . to promote awareness of the roles and functions of the Committee and to promote the Committee as one of national and international standing;
- . to produce working papers from time to time on its Terms of Reference and distribute same to interested persons and organisations;
- . to produce a draft report on references within six months of committee consideration of the reference;





- . to be a means of synthesising on a National basis, the findings of the various State enquiries;
- . to promote efficient, high standard, professional and well presented work within the terms of reference of the Committee;
- . to keep abreast of new developments in matters concerning bioethics.

### 3.4 Committee Membership

#### **Chairperson**

- . Ms Robyn Layton, a Barrister in South Australia and a Commissioner of the Health Insurance Commission was, until March 1989, a Deputy President of the Administrative Appeals Tribunal. Between 1984 and 1986, Ms Layton, [then Judge Layton], chaired the Medicare Benefits Review Committee.

#### **Members**

- . Ms Rebecca Albury, a lecturer in sociology at the University of Wollongong. Ms Albury was a member of the NSW Women's Advisory Council Working Party on Reproductive Technologies. Her research interests have also focused in the area of reproductive health care.
- . Mr Don Chalmers, Head of Law Department, University of Tasmania. Professor Chalmers chaired the Tasmanian Committee of Inquiry into Artificial Conception and Related Matters in 1984/85, and was a Commissioner of the Law Reform Commission of Tasmania between 1982/87.
- . Professor Max Charlesworth, Professor of Philosophy, Deakin University. Professor Charlesworth is a member of the Victorian Government's Standing Review and Advisory Committee on Infertility, and Chairperson of the Advisory Committee of the Monash University Centre for Human Bioethics.
- . Ms Sheryl de Lacey, Clinical Nurse Consultant in the Reproductive Medicine Unit of the Queen Elizabeth Hospital, South Australia. Ms de Lacey also represents infertile people on the South Australian Reproductive Council.



- . Ms Heather Dietrich, a Lecturer and researcher in science and technology policy at the University of Technology, Sydney. Ms Dietrich's interests include the effects of IVF technology on women and genetic engineering on society.
- . Sister Regis Mary Dunne, Director, Provincial Bioethics Centre for the Queensland Catholic Dioceses. Sister Regis Mary, who has a background in microbiology and genetics and extensive training and experience in bioethics, was appointed by the Queensland Government to a special committee, which reported in 1984, to enquire into artificial insemination, IVF and related matters.
- . Professor John Funder, Deputy Director, Medical Research Centre, Prince Henry's Hospital, Victoria. Professor Funder is internationally recognised as an expert in the fields of endocrinology and neuro-endocrinology, and also holds degrees in philosophy and politics.
- . Dr Sandra Gifford, Lecturer, Department of Social and Preventative Medicine, Monash Medical School, Victoria. Dr Gifford was formerly a senior policy adviser to the Victorian Health Department, and now lectures and conducts research on public health policy, community health, community health programs, women's and ethnic health issues.
- . Dr Charles Gurd, a retired Secretary of the Northern Territory Department of Health and ex-Chairman of the Forster Foundation which is responsible for drug rehabilitation. Dr Gurd is President of the St John Ambulance [NT].
- . Rev Colin Honey, Master of Kingswood College, University of Western Australia. Rev Honey lectures and researches in medical bioethics and is a member of the ethics committee at King Edward Memorial Hospital for Women.

- . Professor Con Michael, Professor of Obstetrics and Gynaecology, University of Western Australia. Professor Michael chaired a Western Australian committee which produced a report on the social, legal and ethical issues relating to IVF and its supervision.
- . Ms Philippa Smith, Manager, Policy and Public Affairs, Australian Consumers Association NSW. Appointed to the Committee as a consumer representative, Ms Smith was a senior policy analyst, then acting Secretary General, of the Australian Council of Social Services. She also served as head of the Complaints Unit, Department of Health, NSW, and is currently Chairperson of the Consumers' Health Forum.

### 3.5 Appointments

The Chair is appointed for a period of 5 years. Committee members are appointed, in the first instance, for a period of 3 years. AHMC may extend the appointment for a further period of 3 years. As no greater than half of the membership should be vacated at any one time, consideration now needs to be given to an orderly system to change members. It is proposed to replace 4 members per year, each of whom will come from different states, and if possible, from various disciplines. The first change over will take place following the AHMC meeting in March 1991.



#### 4. REFERENCES

The Commonwealth Minister for Community Services and Health requested in July 1988 that the Committee initially address its terms of reference by bringing to the attention of the AHMC :

- . major new developments in the health field with significant bioethical implications; and
- . inquiries or reviews undertaken by State, Commonwealth or major non-government bodies on bioethical topics and, where appropriate, identify opportunities for co-operative work on these topics.

These general references are on-going in nature.

In July 1988, the Committee was referred 5 topics from the CSWM which had been agreed to by AHMC. Specific resources were then allocated to the Commonwealth to consider these references, being :

- . surrogacy;
- . record keeping and access to information;
- . birth certificates and birth records;
- . counselling;
- . access to reproductive technology.

## 5. PROGRESS REPORT

### 5.1 General References

#### Major new developments in the health field with significant bioethical implications.

Medical science is rapidly advancing into uncharted areas. In many areas new developments are rendered obsolete and superseded by advanced technology before the full bioethical ramifications of these processes are known or understood by the community.

The Committee has responded to this reference by :

- . compiling a comprehensive library incorporating the latest published material pertaining to major new developments;
- . developing links with appropriate local and international agencies to ensure that new developments are brought to its attention;
- . receiving regular reports from Committee members involved in the various fields.

In addition, the Committee developed a report entitled "Developments in the Health Field with Bioethical Implications" [Appendix 4] which was endorsed at the February 1989 meeting of the NBCC for release. The paper raises some of the bioethical issues arising from :

- . developments in DNA technology;
- . costs of health technology : bioethical issues; and
- . non-laboratory diagnostic technology.

The aim of the paper is educative and informative. It does not purport to advise on all new developments nor does it purport to provide answers. Instead, its value is in identifying some issues which need more detailed consideration, and may be the basis for future reference.

Inquiries or reviews undertaken by the State, Commonwealth or major non-government bodies on bioethical topics and, where appropriate, identifying opportunities for co-operative work on these topics.

As this reference is ongoing, the Committee chose to address the task by establishing structures to ensure that the NBCC was well informed of activities in the bioethic related fields and that appropriate organisations were made aware of the role, terms of reference and current operations of the Committee.

To date, this has involved:

- . the Chair and Secretariat visiting States and Territories and attending relevant conferences;
- . developing a mailing list of over 400 agencies with involvement in bioethical issues including relevant international organisations;
- . contacting all relevant agencies to promote the role of the NBCC to enable access to any inquiries or reviews that may be produced;
- . developing and maintaining a comprehensive library of books, journals, reports and newsletters;
- . reporting by committee members on the current inquiries and reviews taking place in their States and within their particular discipline;
- . distributing reports to committee members;
- . distributing working papers to interested organisations on the mailing list.

At present, a pamphlet and a quarterly Newsletter are near completion.



## 5.2 Specific References

### Record keeping and Access to information Birth Certificates and Birth Records.

A working party was established to identify and articulate the issues and the secretariat was detailed to provide background information including preparation of a working paper entitled "Access to Information - An Analogy between Adoption and the Use of Gamete Donation". [Appendix 3] Following 3 meetings of the Working Party and detailed consideration given by the Committee at 2 meetings, a draft report has been prepared which will be ready for circulation to elicit public response in the near future.

The draft report on Record Keeping essentially recommends that information and records concerning children born as a result of gamete donation should be retained; that identifying and non-identifying information be collected on pro forma forms and kept at State linked registries and that access to both identifying and non-identifying information be subject to certain named conditions.

The draft report on Birth Certificates and Records essentially recommends that while States have a responsibility to maintain records, they have no responsibility to initiate genetic background information to a child born of donor gametes, the prime responsibility for this resides with the social parents.

These draft recommendations involve complex issues of privacy, the right to know and the rights of parties involved in donor gamete programs. We will be interested to gain public response to these draft recommendations and expect the ensuing debate will reflect a diversity of views as indeed were reflected during committee discussions.

## Surrogacy

In preparation for the Committee's deliberations concerning this reference, a background paper was prepared which covered the social, legal and ethical aspects of surrogate parenthood and outlines some controversial cases as well as surveying community reaction in Australia and abroad. [Appendix 2] This background paper was released to interested organisation including the relevant Federal and State Government Departments. A Working Group has been established and met following the February meeting. A draft report will be prepared by the Committee following consultation with Australian experts in the field. This draft will be forwarded to international consultants for comment before finalisation and presentation to the Health Ministers.

The remaining two references of Counselling and Access to Reproductive Technology Programs will be addressed in the latter half of 1989. The Committee's work plan outlines the proposed methodology and timing.

### 5.3 Chairperson Activities

In addition to chairing the three meetings of the Committee, Ms Layton has been involved in a range of activities directed towards raising the profile of the Committee, establishing International and Local networks and identifying significant issues. Highlights of these activities are outlined below :

- . World Health Organisation Conference on Healthy Public Policy, Adelaide, April 1988;
- . Seventh Day Adventist Conference, Sydney, April 1988;
- . Nurses' Federation Annual Conference, Brisbane, May 1988;
- . NH & MRC Conference on Human Gene Therapy, September 1988;
- . Annual Biological Sciences Symposium of Family Planning Federation of Australia Inc, March 1989.

### Meetings with:

- . Minister for Community Services and Health and officers;
- . WA Minister for Health;
- . Ministerial staff for the Victorian Attorney-General and staff of Joint Parliamentary Committee;
- . Delegation from the Netherlands discussing ethics of dying and prolongation of life;
- . SA Southern Cross Homes Management Limited;
- . Chairpersons of NH & MRC including its Ethics Committee and Health Care Committee and chairperson of the Australian Law Reform Commission;
- . SA Council of Reproductive Technology;
- . Working Party of Record Keeping and Birth Certificates;
- . Professor Margaret Sommerville, McGill University, Vancouver, Canada;
- . Alto Charo, Legal Analyst, Office of Technology Assessment, Washington DC.

### Workshops

- . Media Skills Workshop, Canberra, April 1988;
- . Monash University Bioethics Course;
- . Kennedy Institute Bioethics Seminar, Washington.

### Travel to the USA to attend

- . Hastings Centre, New York;
- . Task Force, Office of Technology and Assessment;
- . New Jersey Bioethics Commission;
- . Representatives of President's Commission;
- . Biomedical Ethics Board.



#### 5.4 Committee Activities

Since its formal establishment in March 1988, the Committee has held three meetings in August 1988, December 1988 and February 1989.

In addition to these meetings, two Working Groups have been formed to examine :

- . Record Keeping and Access to Information, Birth Certificates and Birth Records

Membership

- Mr Don Chalmers
- Ms Heather Dietrich
- Ms Sheryl De Lacey

- . Surrogacy

Membership

- Professor Max Charlesworth
- Ms Rebecca Albury
- Professor Con Michael

Members of the Committee have been actively involved in promoting the role of the Committee to organisations in their home States and have been liaising with the Ethics Committees and within their various disciplines.

#### 5.5 Secretariat Activities

Following AHMC decision in Canberra to form the Committee, a temporary Secretariat was established in the Central Office of the Department of Community Services and Health. The Secretariat was located in the Departmental Bioethics Unit which was additionally responsible for providing advice to the Department on Bioethical issues. The total staffing for this combined area was seven positions.

The permanent and discrete Secretariat for the Committee was established in Adelaide in January 1989 with four full time positions. The decision to locate the Secretariat in Adelaide is in line with the Department's policies of decentralisation and recognition of the role of State Offices of the Department in policy and corporate management. In addition, the Adelaide based Secretariat facilitates the provision of assistance and support to the Committee Chairperson who is also based in Adelaide.

The relocation of the Secretariat from Canberra to Adelaide naturally created some disruption to the efficient functioning of the Committee and its support. The Adelaide Secretariat consists of completely new staff, and it will take time for the team to function at full capacity.

In addition to servicing the 3 committee meetings and the 2 Working Parties, the Secretariat has been involved in a wide range of activities. These include raising the profile of the Committee, establishing effective networks including the development of a comprehensive Bioethics mailing list, incorporating over 400 individuals and organisations, and developing a comprehensive library and data base.

The Executive Director of the Secretariat attended most of the Conferences and meetings with the Chair, but also a range of meetings with ethics organisations and various departmental staff, conferences including the annual meeting of Registrar-General, Births, Deaths and Marriages, and the Public Hearing of the NSW Law Reform Commission on Surrogacy.

## 6. BUDGET

The Committee was allocated a budget of \$300,000 for 1988/89 which was based on the commencing operations at the beginning of the financial year. This was predicated on the belief that the secretariat would be fully operational from April 1988 and thus, would have completed much of the preparatory investigations regarding the references. As the references were not allocated to the Committee until July 1988, the Secretariat could not commence preliminary research as scheduled and the Committee's timetable was delayed, which partially explains the underspend of the budget.

In addition, allowance was not made in the estimates for the time it requires to establish a new Committee. In particular, a Committee needs to devote time to establishing its modus operandi before it commences work on its Terms of Reference. As demonstrated by the Work Plan and the estimates for the remainder of this financial year, expenditure increases once Working Groups are established and functioning, and the Committee has reports to produce and disseminate.

As a result of the above, the projected underspend for this financial year is \$57,441 and this will be a one-off occurrence. The Committee has taken to its task enthusiastically as demonstrated by work completed to date and the challenging work schedule it has developed for the next financial year.

All structures are now in place to enable the projected budget to be expended and the proposed Work Plan to be implemented.



6.1 Financial Performance 1988/89

ITEM	BUDGET OBLIGATION 'TIL 19/1/89	EXPEN/ EXPEN. FOR 1988/89	ESTIMATED	VARIATION
Committees / Travel	81,9000	43,209	65,508	- 16,392
Printing & Publications	21,000	153	8,253	- 12,747
Consultancy	50,000	-	24,000	- 26,000
Conference Attendance	5,000	870	4,130	-
Secretariat Salaries	*125,000	N/A	125,500	-
Miscellaneous	16,600	1,268	15,168	- 1,432
TOTAL	300,000		242,559	- 57,441

\* Transferred to the Department of Community Services & Health Salary Vote

6.2 Budget 1989 - 1990

ITEM	BUDGET 1988/89	PROPOSED BUDGET 1989/90
Committee Fees / Travel	81,900	97,720
Printing & Publications	21,000	14,900
Consultancy	50,000	48,000
Conference Attendance	5,000	5,500
Secretariat Salaries	125,500	140,000
Miscellaneous	16,600	15,000
NEW ITEMS		
Chairperson's Travel	-	14,603
Chairperson's Per Diem	-	13,180
TOTAL	300,000	348,903
	roll-over	57,441
OPERATING BUDGET 1989/90		291,462

The proposed budget for 1989/90 is based on experience to date and the projections made for the remainder of the financial year. Each year the process will be refined and the estimates will become more accurate. The real cost of supporting a Committee of this nature will be clear once the Committee has experienced a full year of operation. Therefore, flexibility should exist within the budget to allow funds to be transferred between items, thus ensuring the most effective use of funds.

### Explanation of Budgetary Items

#### Committee Fees / Travel

In 1988/89, the Committee met on 4 occasions, which is the minimum laid down in the Modus Operandi. While meetings were productive, too much time elapsed between meetings to allow for the tasks at hand to be completed within a reasonable time frame. Therefore, 5 meetings have been scheduled for 1989/90 which will result in greater productivity and the finalisation of further reports for AHMC consideration. The Committee has meetings scheduled in 4 different capital cities in the coming year. This will enable the Chairperson and Committee members to meet with relevant Government Officials and representatives of key organisations, thus raising the profile of the Committee within States and briefing Committee members of State based issues.

#### Printing and Publications

The Committee will be producing more reports for public consultation and Health Ministers next year, and achieving a higher public profile through the publication of the Newsletter. Nevertheless, the proposed expenditure has decreased from this year's estimate.

### Consultancy

The use of consultancy funds was limited this year due to the late referral of topics to the Committee and the time required to establish and consolidate the Committee's operations. These events will not occur next year, and a consultancy vote of \$48,000 will enable the employment of consultants to report on up to four references.

### Conference Attendance

It is essential that the Committee continues to raise its profile among those in the field, and keep abreast of the latest issues and developments emerging in Bioethics. Conference attendance is one vehicle in achieving this. An allocation of \$5,500, \$500 more than last year, is proposed for this purpose.

### Secretariat Salaries

In the previous budget, the salaries item was based on 4.16 effective full time positions. With the transfer of the Secretariat to Adelaide, the positions have decreased to 4, and the levels of the positions have substantially remained the same. Even so, the projected salary costs have increased from \$125,000 to \$140,000 due to national wage increases and higher increment levels. The Commonwealth Department of Community Services and Health will continue to contribute to the salaries bill by paying the salary on costs.

### Miscellaneous

This item has designed to contribute to the cost of establishing and maintaining a comprehensive Bioethics Library, additional travel costs and administrative expenses. While the activities of the Committee will increase, this budgetary item is expected to decrease.



### Chairperson's Travel

Ms Layton wishes to attend an International Conference to be held in London called "Health, Law and Ethics" between 16 - 21 July 1989 and visit various internationally recognised ethics centres in the United Kingdom and France. Those participating in the Conference are internationally recognised in their fields from USA, Europe and Canada, and the topics covered are of universal significance. The Committee has already established international links with the United States and Canada, mainly as a result of a previous trip to the United States when valuable links were established with experts capable of assisting the Committee with its work on the references. A report, prepared by the Chairperson and Executive Director, entitled "Bioethics Organisations in the USA" details those links. A similar report will result from the Chairpersons proposed trip. A one off budgetary item of \$14,603 is requested to cover the cost of the travel and attendance at the conference, and to allow the Chairperson to visit relevant Bioethics organisations in the United Kingdom and France.

### Chairperson's Per Diem

Ms Layton resigned her position as Deputy President of the Administrative Appeals Tribunal and returned to practice at the Bar from March 1989. In her previous position, she was employed by the Commonwealth Government, so no additional payment was required in relation to her duties as chair. As her employment situation had altered, the Minister for Community Services and Health, approved payment of \$10,000 pa to compensate for time devoted to Committee work and a contribution towards the telephone costs. Ms Layton has calculated that she spends at least 58 days per year on Committee business and has requested appropriate compensation. Therefore, a new budgetary item of \$13,180 has been incorporated into the budget for 1989/90.

In summary, the Committee's budget of \$300,000 for 1988/89 will be underspent by an estimated \$57,441. If this amount was rolled over to the next financial year, then the Committee would require \$288,562 for its operations for 1989/90. This is a net decrease in the amounts to be contributed by the Commonwealth, States and Territories. It is envisaged that all funds will be expended in 1989/90 so the budget for future years will be in the order of \$340,000 including wage and CPI increases.

## 7. WORKPLAN

The proposed workplan is challenging, but achievable. It is based on the committee's experience that a 9 month period is required to produce a final report on a reference. This time-frame allows a Working Party to meet on 2-3 occasions to establish the issues and suggest possible solutions, and two full meetings of the Committee. The first to discuss and agree principles and the second to consider the report drafted in accordance with these principles. The time frame includes a period of two months for public consultation before the report is finalised for presentation to the Health Ministers.

Experience of Australian and American committees has demonstrated that it is difficult for a small Secretariat to adequately support more than one Working Party. Therefore, the commencement of work on specific references has been staggered, while the consideration of the general references will be ongoing.

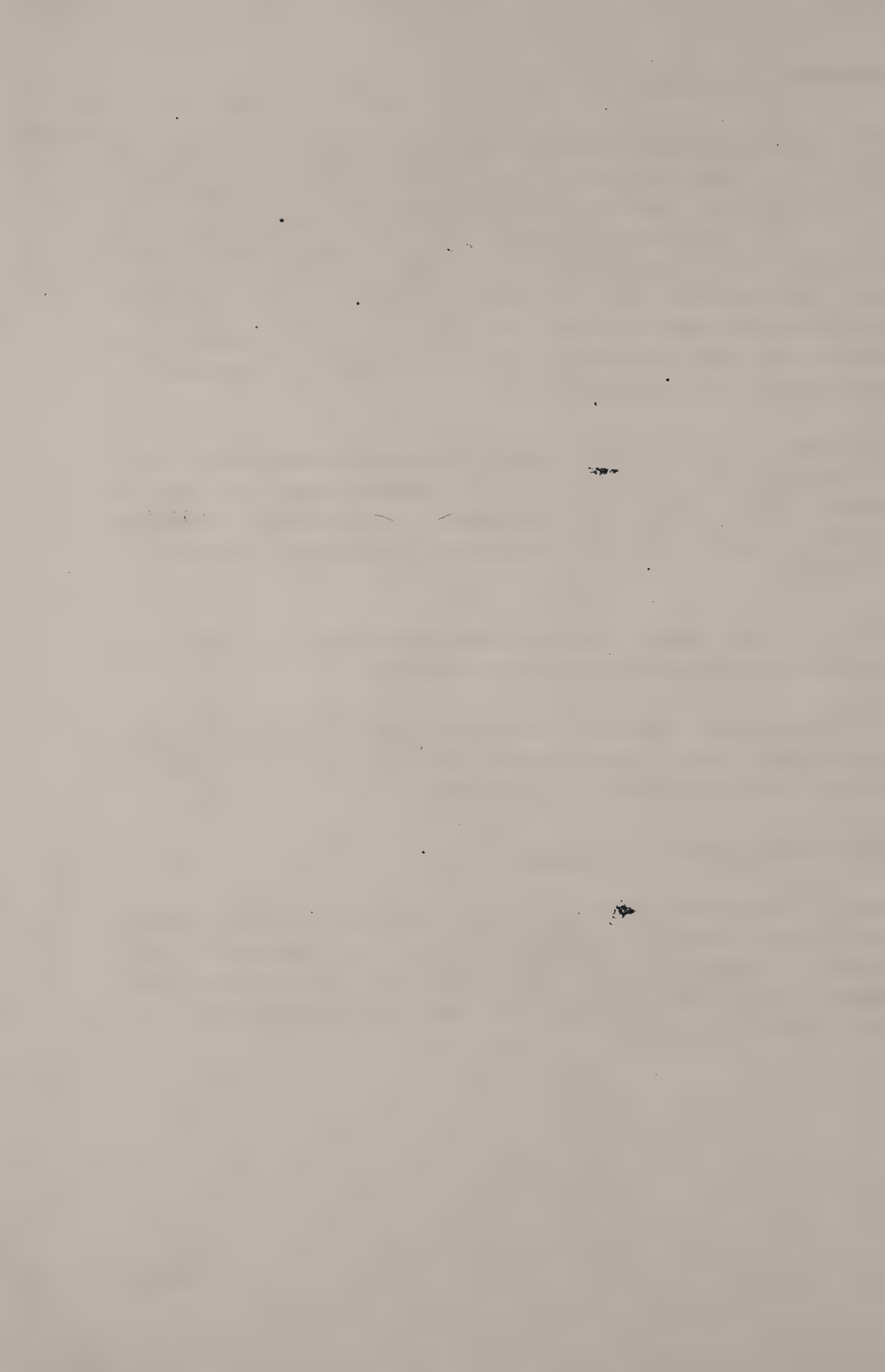
The Work Plan suggests that the Committee will be in a position to commence work on a new reference in January 1990.

The Committee has identified the following areas as requiring ethical consideration from a national perspective. AHMC may wish to consider these as future references for the Committee.

### Non-Laboratory Diagnostic Technology

Recent development of techniques for the preparation of highly purified and specific antibodies - monoclonal antibodies - has facilitated a rapid spread of diagnostic tests. Self testing kits for pregnancy, blood, sexually transmitted diseases and AIDS, are available overseas and to a lesser extent in Australia.





International experience has highlighted the potential problems associated with the free availability of self testing kits. Before Australia begins to experience such difficulties, the following questions should be answered.

- . Should there be limits on the availability of the tests, who will control their quality, and how will this be regulated?
- . How will users be adequately trained in the use of the tests and the significance of the results?
- . What may be the consequences of false self diagnosis results, eg false HIV positive and negative readings?
- . Will the use of home test kits increase patient initiated utilisation of general practitioners?

In addition to the ethical and regulatory questions, there are Health resource implications. It is postulated that 'Do It Yourself' testing may lead to increased consultation with medical practitioners, with a resultant increase in the Medicare Bill.

The report "Developments in Health Care with Bioethical Implications" [Appendix 4] contains a more detailed discussion of these issues.

#### Initiation, Continuation or Withdrawal of Life Sustaining Treatment

Occasions frequently occur in the course of medical practice when a decision is made to initiate, continue or withdraw active treatment which seems necessary to sustain the patient's life. The complexity of the decision making process is highlighted by the need to balance medical, legal, economic and ethical considerations.

It is known that a substantial proportion of limited health resources may be committed to extending the lives of people for a short period. It is reported that in the United States nearly one third of the available Medicare budget was consumed in extending the lives of people for less than one year. There are further difficulties and considerations dependent on the age of the recipient and the circumstances of the suggested treatment; whether the person is old, an accident victim, a child or premature baby. However, the following questions would apply to all;

- . Who should make the decision?
- . What are the appropriate criteria to be used?
- . What are the economic implications of decisions in this area?

### Organ Transplants

Advances in the technology of organ transplants have led to two developments which are important to medical planning and have economic and ethical implications in the making of public policy.

- . improvement in diagnostic procedures, surgical techniques and treatment have rendered once difficult procedures, such as kidney and corneal transplants, almost routine. Improved technology has led to greater success and in a rapid expansion in the variety of transplants being attempted and offered as therapy, eg heart, heart-lung, foetal pancreas implants.
- . the demand for organs exceeds supply thus raising such ethical issues as the selling of organs, the use of foetuses and still births as sources of spare parts and the deliberate production of foetuses for organs and other materials.



The questions raised by the advances in organ transplant technology require the balancing of economic, ethical, legal and medical considerations.

- . Is it appropriate to allocate substantial amounts of limited health resources to the less-successful or 'experimental' transplants?
- . What are the morally and socially acceptable sources of supply of donor organs?
- . Do patients have a 'right' to organ transplant therapy which may improve their quality of life, or even be essential for sustaining life?

#### Post-natal care of premature infants

Demand for post natal care facilities are growing, primarily as a consequence of advances in medical technology enabling younger infants to be kept alive. Infertility procedures, such as IVF, have also increased the number of premature and multiple births.

However, the long term consequences of medical treatment are uncertain in that one child may thrive but another may suffer severe disabilities as a direct result of medical intervention. The quality of life for child and parents is often a factor in deciding upon the level of active medical support provided for a premature infant.

The high cost of care for each infant is also of concern. It is estimated that the cost of medical treatment per surviving infant is \$72,000 for infants under 1kg and \$2,587 for those over 2.5kgs. The total cost of neo-natal care has become a substantial cost to the available health budgets.

The issues raised for public policy include :

- . Who should decide upon the allocation of life sustaining resources to premature infants?
- . Should anticipated quality of life of the infant be a consideration in that decision?
- . Should cost considerations play a part in that decision?
- . What are the rights of the parents of a child?

#### Health Resource Allocation

The issue of the allocation and distribution of available health care funds has become a growing concern for governments and the community. An increase in technology and the availability of expensive treatments have, in turn, increased the demand for and cost of health care funds.

There is a general interest as to the present allocation system of health care funds in Australia and a consequent need to consider a future process for evaluation of allocation decisions, taking into account ethics, principles and desired outcomes.

An Information and Discussion paper on health resource allocation would help to clarify the background for other issues being considered by the Committee. Such a paper would provide the Health Ministers with information on current resource allocations and their ethical implications.

## Human Embryo Experimentation

It is agreed that experimentation on human embryos is important for the development of knowledge of human biology and genetics, as well as allowing the early identification and prevention of genetic disorders. Conversely, concern has been expressed that to allow experimentation on human embryos is to allow interference with human life. This has led to a debate about the point at which the embryo becomes a person with human rights.

The proposal of the Warnock Report in Britain is to allow embryo experimentation up to the fourteenth day after fertilisation. The report concluded that up to that point, the embryo had very few of the characteristics of a person.

However, in Australia, the Victorian Government has enacted legislation [1986] which imposes criminal penalties if ova are fertilised for experimental purposes. The use of "spare" embryos is also prohibited for a variety of purposes, including genetic screening, sex testing and embryo splitting. Other States have yet to enact legislation but a variety of reports have been prepared on the topic.

A national approach is desirable in this instance as differing State policies enable the possible transfer of research centres and materials to States where legislation does not exist.

The issues that need to be addressed include the following :

- . What are the ethical boundaries for medical research in this area?
- . Is uniform legislation desirable or feasible?



Many of the proposed references discussed above have in part been addressed or are being considered by NH&MRC and its sub-committees. At times the ethical issues are overshadowed by the medical and regulatory nature of the issue at hand. The Committee is interested in investigating the possibility of collaborative work with other relevant committees to avoid possible duplication and to ensure that all facets of a reference are well explored.

JUNE

MAY

APRIL

MARCH

FEBRUARY

JANUARY

DECEMBER

NOVEMBER

OCTOBER

SEPTEMBER

AUGUST

JULY

JUNE

MAY

APRIL

REFERENCES

1 Record

Keeping and

Access to

Info Birth

Certificates &

Birth Records

2 Surrogacy

Issues Paper

3 Counselling

Issues Paper

4 Access to

Reproductive

technology

5 New

Developments

in the Health

Field

Report

finalised

Report formally presented

to AHMC & CSWM

Report Finalised

Report Presented to AHMC & CSWM

Report Revised

Public Consultation

Report Presented to AHMC & CSWM

Issues Paper

Report Revised

Public Consultation

Report Revised & Finalised Report Presented to AHMC

Secretariat & Committee Members provide updates at every meeting

## REFERENCES

6 Inquiries or

Denizens  
Secretariat provides updates every meeting

undertaken by

State, Comm or

Major non-

## Government

bodies on

bioethical

topics

7 "New Reference"

## 8 Annual Report

Consolidated Report

presented to AHMC

## Issues Paper

## Outline Endorsed

**Port Endorsed**

Annual Report presented

to AHMC

Report Presented

Committee Meetings

## Working Parties

Newsletter Dispatched



## 8. RECOMMENDATIONS

In line with the discussion in the body of the report, the Committee puts forward the following recommendations. AHMC is requested to :

- . note this report, including the attached documents and agree to their release to the CSWM;
- . endorse the proposed Work Plan;
- . approve the proposed budget of \$291,462 including:
  - the roll over of \$57,441 from 1988/89 to 1989/90;
  - the new items of Chairperson's per diem 1989/90 and the cost of Chairperson's travel to the International Conference.
  - agree to flexibility between line items in the budget.
- . direct new references to the Committee.
- . agree to the change over of 4 members of the Committee per year commencing the first meeting after the AHMC of 1990.

PRODUCT MONITOR

DECEMBER 1988/JANUARY 1989

Prepared by:

MARKETING DEPARTMENT  
FEBRUARY 1989





**NBCC PUBLICATION**

**NB 18**